House of Representatives

General Assembly

File No. 266

February Session, 2002

Substitute House Bill No. 5686

House of Representatives, April 2, 2002

The Committee on Public Health reported through REP. EBERLE of the 15th Dist., Chairperson of the Committee on the part of the House, that the substitute bill ought to pass.

AN ACT REQUIRING THE SCREENING OF NEWBORNS FOR METABOLIC DISEASES.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. Subsection (a) of section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (*Effective October 1, 2002*):

(a) The administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care an HIV-related test, as defined in section 19a-581, a test for phenylketonuria and other metabolic diseases, hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia and such other tests for inborn errors of metabolism as shall be prescribed by the Department of Public Health. The tests shall be administered as soon after birth as is medically appropriate. If the mother has had an HIV-related test pursuant to section 19a-90 or 19a-

593, the person responsible for testing under this section may omit an HIV-related test. The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover all expenses of the comprehensive screening program including testing, tracking and treatment. The fees to be charged pursuant to subdivision (3) of this section shall be set at a minimum of thirty-five dollars. The commissioner shall adopt regulations, in accordance with chapter 54, specifying the abnormal conditions to be tested for and the manner of recording and reporting results. On or before January 1, 2003, such regulations shall include requirements for testing for long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-CoA dehydrogenase (MCAD).

Sec. 2. *(Effective July 1, 2002)* The Department of Public Health shall purchase two tandem mass spectrometers to be used for screening newborns for metabolic diseases.

This act shall take effect as follows:	
Section 1	*October 1, 2002*
Sec. 2	*July 1, 2002*

PH *Joint Favorable Subst.*

The following fiscal impact statement and bill analysis are prepared for the benefit of members of the General Assembly, solely for the purpose of information, summarization, and explanation, and do not represent the intent of the General Assembly or either House thereof for any purpose:

OFA Fiscal Note

State Impact:

Fund-Type	Agency Affected	FY 03 $	FY 04 $
GF - Revenue Gain	Department of Public Health	548,250	731,000
GF - Cost	Department of Public Health	343,200	243,200
GF - Cost	Department of Mental Retardation	See Below	See Below
GF - Cost	Department of Social Services	Minimal	Minimal
GF - Savings	Department of Social Services	Potential Indeterminate	Potential Indeterminate
GF - Cost	University of Connecticut Health Center	Minimal	Minimal

Note: GF=General Fund

Municipal Impact:

Effect	Municipalities	FY 03 $	FY 04 $
Cost	All Municipalities	Minimal	Minimal
Savings	All Municipalities	Potential Indeterminate	Potential Indeterminate

Explanation

Passage of this bill will result in a significant revenue gain to the state and a cost to the Department of Public Health (DPH). It could also generate potentially significant savings to state and municipally funded health insurance and other programs. Specific impacts are as follows:

Increase Fee for Newborn Genetic Testing

The bill increases the newborn testing fee collected by DPH from the current $18 to at least $35, effective October 1, 2002. It is anticipated that the commissioner of public health will initially implement a fee of exactly $35. This will generate additional FY 03 General Fund

revenues of $548,250 (reflecting three-quarter year implementation) and an ongoing revenue gain in FY 04 and subsequent fiscal years of $731,000. This calculation is based on an expected 43,000 births annually.

As the number of births at Dempsey Hospital is relatively low (approximately 600 annually), its increased fee payments would be minimal (approximately $10,200). It is assumed that the majority of these additional costs would be recouped by the University of Connecticut Health Center via patient billings.

At such time when the fee increase is reflected in future contract negotiations between: (a) the Department of Social Services and Medicaid managed care organizations, (b) the state employee plans and their carriers, and (c) municipalities and their health insurers, a minimal state and municipal cost will ensue.

Expand Newborn Genetic Testing

The bill implements an enhanced newborn genetic testing program, effective January 1, 2003. The Department of Public Health projects that ten (10) confirmed cases of infants having the specified amino acid/fatty acid disorders would be identified each year in Connecticut. Early identification and treatment of these children will reduce the frequency of some medical complications and possible developmental delays commonly associated with these disorders.

To the extent that any resulting health care savings are passed on to the state through future negotiated contracts for Medicaid managed care programs, a future indeterminate savings to the Department of Social Services will result. Any such savings would be partially offset by reduced federal financial participation. A similar potential savings may result for state and municipal employee health insurance plans should health care costs be significantly reduced due to enhanced early identification and treatment.

The enhanced testing program may also impact the demand for

services under the Department of Mental Retardation's (DMR) Birth-to-Three program. The Birth-to-Three program is an entitlement for infants and toddlers from age 0-3 with developmental delays. It is uncertain to what extent this system would be impacted by changes in caseload due to this bill. Services may be accessed earlier, however rapid diagnosis and treatment may mitigate long-term development of associated disabilities and the resulting need for other services. The estimated average cost per year of services for an infant and toddler in the Birth-to-Three program is $7,100. It should be noted that sHB 5019, (the Appropriations Act, as favorably reported by the Appropriations Committee) includes additional funding of $1.2 million in the Birth-to-Three program for a projected increase in caseload unrelated to this bill.

The Department of Public Health will incur an FY 03 cost of approximately $343,200 to reflect initiating State Laboratory testing for these disorders. Included in this sum is $300,000 to allow the agency to purchase chemical reagent kits necessary to conduct the new tests and $43,200 to support a transport contract with an overnight courier service to ensure timely delivery of specimens. In FY 04 and subsequent fiscal years an ongoing cost of approximately $243,200 will be incurred as the number of needed reagent kits would decline following the initial year, as fully validated testing procedures would be in place. Funding for these expenses has not been included within sHB 5019.

Equipment costs of approximately $610,000 associated with the purchase of two tandem mass spectrometers are anticipated to be supported by previously authorized Capital Equipment Purchase Fund (CEPF) dollars. The agency's anticipated FY 03 CEPF allocation is $965,546.

Confirmation testing and final diagnosis of these disorders, as well as subsequent family counseling and treatment, will likely occur at one of two genetic disease treatment centers in Connecticut (Yale University, University of Connecticut/Connecticut Children's Medical

Center). While the bill does not explicitly mandate enhanced state support for these programs, DPH has historically provided them funding for their work with families in which children having any of the eight genetic disorders for which newborns are presently screened are identified. A future potentially significant cost would result should passage of this bill lead to demand upon this system which cannot be accommodated without additional state resources.

OLR Bill Analysis
sHB 5686

AN ACT REQUIRING THE SCREENING OF NEWBORNS FOR METABOLIC DISEASES

SUMMARY:
This bill sets a $35 minimum fee the Department of Public Health (DPH) must charge hospitals for its newborn screening program. By law, the DPH commissioner must establish a fee that covers all program expenses, including initial testing; tracking to assure that infants who initially test positive are referred for comprehensive testing and parent counseling; and treatment. The current fee is $18. The bill also requires DPH to buy two tandem mass spectrometers to screen newborns for metabolic disorders.

Current law requires screening for eight named conditions, including phenylketonuria, biotinidase deficiency, and hypothyroidism, and "other inborn errors of metabolism." It also requires the DPH commissioner to adopt regulations specifying the conditions to be tested for. The bill requires these regulations to include, by January 1, 2003, testing for medium-chain acyl-CoA dehydrogenase (MCAD) deficiency and long chain 3-hydroxyacyl CoA dehydrogenase (LCHAD) deficiency. And it requires testing for other metabolic diseases.

EFFECTIVE DATE: October 1, 2002 for the fee increase and testing changes; July 1, 2002 for the mass tandem spectrometer purchase.

BACKGROUND

Related Law

Pursuant to PA 01-9, June Special Session, DPH submitted a report to the Public Health and Appropriations committees on February 20, 2002 on the feasibility, cost, and time frames for establishing testing programs for LCHAD and similar protein deficiencies.

LCHAD and MCAD

LCHAD and MCAD are genetic deficiencies that result in an inability to break down fatty acids as a usable energy source. LCHAD can result in dangerously low blood sugar levels, poor muscle tone, and heart problems. It can also cause medical complications in the pregnant mother, including liver failure. Children with MCAD can develop seizures, respiratory failure, and heart problems. Treatment for both is based on diet.

COMMITTEE ACTION

Public Health Committee

Joint Favorable Substitute
Yea 23 Nay 0